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ABSTRACT

This literature review on young adults with mental retardation brings together two previously disparate areas of research, community integration and young adult development. After a discussion of various theories addressing the young adulthood stage of development, the paper summarizes research on young adults with mental retardation in the following domains: (1) social integration (findings emphasize the passive, solitary, family-dependent nature of their lives and the need to promote greater social integration); (2) recreational/leisure integration (stresses the need for greater opportunities to learn and enjoy recreational activities); (3) economic integration (points out that the right to manage one's own income should be respected as much as possible); and (4) support services (in the areas of residential, vocational, and other services) and barriers (especially attitudinal) to community integration. Includes 110 references. (DB)

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# Community Adjustment of Young Adults With Mental Retardation:

# A Developmental Perspective

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Abstract

Several approaches to the study of community adjustment have been conducted over the years, but few, if any have examined the development of young adults with mental retardation relative to developmental tasks for young adults in general. This review of the literature is an effort in that regard. The present review brings together two previously disparate areas of research, community integration and young adult development, with the hope of expanding the conceptual and theoretical framework of both.

Community Adjustment of Young Adults With Mental Retardation:

A Developmental Perspective

The adjustment of young adults with mental retardation remains a crucial issue for all human service providers. No longer does adjustment imply simply the physical integration of persons with disabilities into community settings. Rather, it means the complete adjustment and integration of the whole person into community life. Whether one describes community adjustment as a process, an outcome, a philosophy, or a multidimensional concept (Bachrach, 1981), community adjustment has become synonymous with the term quality-of-life, a quality that depends in large part on one's level of happiness and success in socially sanctioned, age-appropriate tasks.

Much has changed about the way in which young adults with mental retardation have reentered communities in recent years. State and federal laws as well as precedential court cases have codified expectations that people with disabilities have the opportunity to live, work, and participate in typical community settings (e.g., the Individuals with Disabilities Education Act, PL 101-467; the Americans with Disabilities Act, PL 101-336; and the Developmental Disabilities Assistance and Bill of Rights Act, PL 101-496). Each year, proportionately fewer people with mental retardation live in institutions (63% in 1977; 41% in 1988) and more live in homes with 15 or fewer other people (21% in 1977; 45% in 1988) (Amado, Lakin, & Menke, 1990). Likewise, increasing numbers of persons with mental retardation work in typical work settings (9,882 in 1986; 70,000 in 1990; Wehman, 1991). While there appears to be consensus on the notion that "institutional care is unnecessary and inappropriate for the vast majority of (if not all) persons with developmental disabilities" (Lakin, Hill, & Bruininks, 1988, p. 26), there remains disagreement on the dimensions and speed with which this integration should occur (Taylor, 1988).

Kregel, Wehman, Seyfarth, and Marshall (1985) have suggested that domestic, recreational, and community skill building tasks serve as the core elements of training programs designed for people with mental retardation living in community settings, but have buffered their recommendations with the caveat that little data exist on which to evaluate the success of such training programs. This difficulty

in evaluating the structure of training programs is related to a broader difficulty in defining facets of community adjustment for persons with mental retardation (Lakin, Bruininks, & Sigford, 1981). To address these issues, researchers at the University of Minnesota have proposed a model of adjustment based on four empirically validated dimensions: Social Network Integration, Recreational/Leisure Integration, Economic Integration, and Need for Support Services (Bruininks, McGrew, Thurlow, & Lewis, 1988, in press; Ittenbach, Bruininks, Thurlow, & McGrew, 1991; McGrew & Bruininks, 1988). Despite the importance of conceptual frameworks, however, there is more to the concept of adjustment than simple outcomes and a chronology of normative life events; as Blalock (1988) has described:

> a realistic perspective requires more attention to the spectrum of abilities and needs presented by *each individual* [italics added] in each facet of life; strengths and weaknesses in all areas of living fall along a continuum that remains open to change, depending on one's experiences. (p. 4)

One perspective may come from the field of developmental psychology. Unfortunately for young adults, most well known theorists such as Freud and Piaget have emphasized the early years and have all but ignored the years from adolescence onward. However, a few theorists, most notably Erikson (1968), Levinson (1986), and Havinghurst (1972), have taken have taken a lifespan approach to the study of human development and, while they have not focused on young adulthood exclusively, they have given credibility to the notion that important developmental events occur beyond the early years. In the simplest case, Erikson considers the struggle between intimacy and isolation to be a major developmental task of young adulthood. Levinson, focusing on adults of all ages, considers making choices in such areas as intimacy, employment, friendship, values, and lifestyles to be the major tasks of the transition years. For Havinghurst (1972), young adulthood is as much a process as it is a time for making choices. During young adulthood one must do such things as find a mate, begin a family, and assume parental responsibilities; one must experiment with various living arrangements and begin assuming management responsibilities for a home, for oneself and for others. A career, appropriate social networks, and civic responsibilities are additional key responsibilities of the young adult.

There is one theorist for whom young adulthood is not simply one of many stages of development, but, rather, the major area of inquiry. Chickering (1969) has outlined seven dimensions of development, referred to as vectors, along which development generally occurs. The name vector is chosen for the geometric expression which implies direction and magnitude, a reference that Chickering states may be as much of a spiral as linear. Though Chickering believes there to be a sequence to one's development, the sequence is neither completely age-based nor invariant. Whether one refers to them as stages, tasks, milestones, or trends, Chickering (1969) has reported that all young adults have seven major areas of development in common: competence, emotions, autonomy, interpersonal relationships, purpose, identity, and integrity (p. 8). Growth along any one dimension is not dependent on any one vector; however, unresolved conflicts at earlier phases will likely inhibit development at later stages.

Given the recent emphasis on community adjustment, the exceptionally large number of young adults with mental retardation living or preparing to live in community settings, and the near void of information on developmental components of young adulthood, it is now time to examine developmental tasks for young adults with mental retardation, specifically, and with regard to what is known about the developmental sequence in general. This review of the literature is an effort in that regard. By bringing together two previously disparate areas of research, community integration and young adult development, it is hoped that the conceptual and theoretical framework of both will be extended. The following discussion is organized around the four domains reported in the Bruininks, McGrew, Thurlow, and Lewis (1988; in press), Ittenbach, *et al.* (1991), and McGrew and Bruininks (1988) research.

## Social Integration

A conceptualization of people as inherently social animals has existed since the time of Aristotle. However, it has only been in recent years that the influence of social relationships for young adults with disabilities has received careful attention. The importance of regular social contact with valued others, especially peers, cannot be underestimated. Social relationships contribute to one's capacity

to relate to others, development of social controls, and acquisition of societal values (Hartup, 1991). Evidence has accumulated linking the quantity and quality of one's social relationships, often referred to as networks, to a wide variety of outcomes including physical and psychological well-being (Cohen & Syme, 1985; Kessler & McLeod, 1985). Social ties with significant others are, therefore, crucial for the successful adjustment of adults with and without disabilities (Edgerton, 1967; Edgerton & Bercovici, 1976; Hartup, 1991; Landesman-Dwyer & Berkson, 1984). Despite recent emphases on socialization and normalization of interactions with others (Edgerton, 1967; Edgerton, Bollinger, & Herr, 1984; Landesman-Dwyer & Berkson, 1984), relatively little is known about the nature of relationships formed by young adults with mental retardation or the impact of these relationships on one's quality-of-life. Given the need for instrumental and emotional support from others, in young adults in general and young adults with mental retardation in particular, it is somewhat puzzling that the impact of social relationships in this population has not been studied far more frequently.

Social relationships serve many important functions as an individual transitions from adolescence to adulthood. Social support available through relationships with others appears especially crucial to young adults with mental retardation as they confront salient developmental tasks such as: identity, autonomy and independence, competence and self-efficacy, long-term vocational goals, and long-term social relationships. Research suggests that while one's social relationships with others influence and are effected by the manner in which the individual handles these tasks, the overwhelming majority of young adults with mental retardation do not have the same opportunities for social relationships as their peers without disabilities (Abery, Thurlow, Bruininks & Johnson, 1990; Meyer, McQuarter, & Kishi, 1984). Results from recent investigations suggest that from middle childhood to adulthood, the social lives of individuals with mental retardation remain highly restrictive and focus almost exclusively on the family and paid caregivers (Abery *et al.*, 1990). Few persons with moderate to severe levels of mental retardation appear to have neighborhood or independent community-based friends (Hill, Rotegard, & Bruininks, 1984; Hill, Lakin, Bruininks, Amado, Anderson, & Copher, 1989). Further, contacts with peers are often confined to contexts that fail to generalize to multiple settings and those that are

formed generally fail to provide the young adult with sufficient social support, making coping with the transition from adolescence to adulthood extremely difficult (Abery,. Thurlow, Johnson & Bruininks, 1989).

It is assumed by many individuals that the limited social contacts of young adults with mental retardation result from a lack of social skills; however, findings suggest that this is often not the case. Social skills assessments as well as qualitative data suggest that many young adults with mental retardation fail to develop rich social lives as a result of a multitude of barriers (e.g., accessibility of services, transportation, outreach programs, public's lack of knowledge, and overprotection by significant others) that exist within the family and community (see Support Services section). Findings from follow-up research suggest that physical integration alone does not guarantee that young adults with mental retardation will establish and maintain desired social and interpersonal contacts in the community (Abery *et al.*, 1990; Bruininks, Thurlow, & Lange, 1987; Rosen & Burchard, 1990). While school-based efforts to enhance social interaction between persons with and without disabilities have met with some success, such programs are rarely available for young adults who have transitioned from school to employment and from home to the community. In addition to having few friends, young adults with mental retardation frequently lack friends, companions, and acquaintances who do not have disabilities (Abery *et al.*, 1989). And, when such relationships do exist, they are often short-lived (Kennedy, Horner, & Newton, 1989; Zetlin & Murtaugh, 1988). A point of special concern with respect to research findings has been that for many persons with mental retardation, friendships and social relationships tend to decrease with age--at a time when social skills are increasing (Abery *et al.*, 1989).

While an individual's social relationships have a direct effect on the quality-of-life they experience in the community, these affiliations also have an impact on the ease with which an individual is able to traverse the many developmental tasks that accompany the transition process, tasks that are faced by young adults with as well as without disabilities. Erikson (1963), among others (e.g., Adams & Fitch, 1982; Munro & Adams, 1977), has proposed that establishing an identity is a gradual process that

extends into early adulthood and is necessary before one can enter into truly intimate relationships with other adults (Fitch & Adams, 1983; Whitbourne & Tesch, 1985) or set and actively work toward the attainment of long-term vocational goals (Archer, 1982). The establishment of an identity as well as one's sense of self-esteem are based to a large extent on the social give and take that occurs between the individual and significant others. Because self-knowledge and self-esteem are influenced by the way in which others perceive and react to behavior (Cooley, 1902; Harter, 1983), the restricted social lives of young adults with mental retardation can be expected to place them at a distinct disadvantage in the resolution of this crucial developmental task.

A second developmental task of early adulthood involves the exertion of increased autonomy and independence, a task that virtually all theorists consider important for the development of adult roles. As the young adult transitions from the family to the community, co-regulation, or joint decision-making with parents gives way to self-determination (Levinson, 1986; Havinghurst, 1972). For all adolescents and young adults, interactions with significant others of the same status play an important part in the development of autonomy (Hartup, 1991). Interactions in which decisions are not imposed by those in authority provide opportunities for choice-making and the exertion of personal control that are not always available in other contexts. For the young adult whose social network consists almost entirely of family and professionals, a lack of friends can result in few opportunities to exert choice, make decisions, and engage in interactions that facilitate the development of skills necessary for independence and autonomy.

Two hallmarks of the developmental transition from youth to adulthood are the setting of short- and long-term vocational goals and the attainment of full-time employment. An occupation and the economic self-sufficiency that it produces has an impact on one's quality-of-life in both a direct (increased independence and autonomy) and indirect (feelings of competence and self-worth) manner. Employment outcomes for young adults with mental retardation, although improved over past decades, remain far from optimal. For example, there continue to be many more young adults who wish to work in competitive and supported employment settings than positions available and job

loss following placement remains a persistent problem (Brickey, Browning & Campbell, 1982; Rusch, 1986). When workers with disabilities lose jobs, social inadequacies and social skill deficits are among the reasons most frequently cited (Salzberg, Lignugaris-Kraft, & McCuller, 1988). The lack of a supportive network of friends upon whom to model one's behavior may be a factor that contributes to these deficits. Research results also suggest that in the work setting itself, the majority of contact between workers with and without disabilities is concentrated on job performance with very little contact between employees during breaks or after work hours (Shafer, Rice, Meltzer, & Haring, 1989). Without the opportunity to develop social relationships with co-workers, young adults with mental retardation do not have available the social support necessary to effectively cope with stressors emanating from the work setting.

Results of research on the social relationships of young adults with mental retardation emphasize the passive, solitary, family-dependent, nature of their lives and suggest a need to identify programs that promote a stronger sense of interpersonal identity and belonging within their community, especially programs involving peers without disabilities, on a regular basis, and in socially valued activities. In addition, they will need to insure that young adults have access to the same experiences and environments as peers without disabilities so that they can actively choose with whom they desire to establish social relationships rather than having well-meaning parents or professionals do this for them. If human services personnel, educators, and families are sincerely interested in improving the quality-of-life of persons with mental retardation, opportunities to develop and maintain social relationships within integrated environments must be made available. Opportunities for social integration will also provide a very important benefit for individuals without disabilities as they learn to accept and appreciate individual differences.

## Recreational/Leisure Integration

The ability to choose how to spend one's leisure time, in recreation or play, is one that many young adults take for granted. From childhood, most individuals pursue a variety of sports and leisure activities which they continue to enjoy through middle- and older-adulthood. As alluded to previously,

young adults with mental retardation often do not have the same opportunities as young adults without mental retardation to learn recreational skills, and, as a result, cannot effectively choose how to spend their leisure time (Datilo, 1987). Because of limited employment opportunities, persons with disabilities generally have more leisure time than most others (Ball, Chasey, Hawkins, & Verhoven, 1976; Verhoven, Schleien, & Bender, 1982), yet, they participate in recreational activities less often than young adults without disabilities (Datilo, 1987; Katz & Yekutiel, 1974). In contrast to peers without mental retardation who often spend their free time shopping, dating, going out to dinner or movies with friends, and attending sporting events, young adults with mental retardation have been reported to spend their free time watching television, listening to the radio or records, or simply staying at home (Kregel *et al.*, 1986; Minnesota Department of Education, 1987). For many young adults living in community homes or institutions, leisure activities are planned by staff and tend to be passive rather than active (Aveno, 1987; Bruininks & Chvat, 1989).

The importance of learning and participating in self-affirming recreational activities has been well-established. Recreational activities provide opportunities for social interaction, development of self-esteem and self-confidence, experimentation with independent choices, and opportunities for spending leisure time in enjoyable individual and group activities. Leisure and recreational time can be an important psychological outlet as well as a means to a healthier and more fulfilling lifestyle, tendencies that are true for all young adults, with or without mental retardation (Rynders, & Schleien, 1991; Schleien, & Ray, 1988; Verhoven *et al.*, 1982). For individuals transitioning into adult life, recreational skills are an integral part of interacting with others in appropriate ways and are considered to be avenues of social acceptance in everyday life. Young adults with mental retardation, similar to their peers without mental retardation, are indeed capable of learning recreational skills. Two such examples are the Special Olympics and the Unified Special Olympics programs in which the performances of many athletes meet or exceed the performance levels of adults without disabilities.

While the skills can be learned, young adults with mental retardation frequently require more instruction, reinforcement, and opportunities to practice newly acquired skills, making it necessary to

provide specific opportunities for leisure and recreational skill instruction. Unlike their peers without mental retardation, young adults with mental retardation are less likely to have spontaneously learned play skills (Wehman, 1977). This issue is receiving increasing attention, particularly by those involved in adapted physical education, transition, and community integration programs (Blalock, 1988; Ray & Burke, 1990; Schleien & Ray, 1988). Awareness about individual needs and personal preferences is also increasing. Just as individuals without disabilities consider their own unique situations and goals when choosing leisure activities, so must young adults with mental retardation. It is the sense of empowerment that allows for the facilitation and execution of individual choices. Current programs developed to enhance recreational skills of these individuals range from specific individualized skill instruction programs to integrated community programs to international events such as the Special Olympics.

Special Olympics and it's affiliate the Unified Special Olympics are perhaps the most well-known and well-established programs facilitating participation in sports by persons with mental retardation. Increased interaction between persons with and without disabilities, increased use of recreational facilities, increased positive visibility, and training and competitive opportunities similar to those of athletes without handicaps are some of the reported benefits of this program (Orelove, Wehman, & Wood, 1982). Despite its long history and strong community support, however, many professionals criticize the Special Olympics program for its segregation and perpetuation of stereotypes (Brickey, 1984). By providing the time, training, and appropriate learning and participative opportunities, Special Olympics and Unified Special Olympics serve as a stepping stone to other less segregated but equally competitive programs that foster a successful entrance into community programs (Dinn, Krebs, & Staur, 1989; Shriver, 1989).

Integrated recreational/leisure programs are gradually becoming more prevalent. Led by the normalization movement, age-appropriate sports and leisure activities, and training methods for overall fitness (Schleien & Ray, 1988), a variety of community recreation groups, outdoor adventure organizations, and community centers have developed recreational and leisure programs to integrate

persons with disabilities (Rynders & Schleien, 1991). Literature on evolving recreational and leisure programs that stress integration into existing programs is increasing rapidly (Datilo, 1987; Ray, Schleien, Larson, Rutten, & Slick, 1986; Rynders & Schleien, 1991; Schleien & Ray, 1988; Wehman & Schleien, 1981; Wilhite, Reilly, & Teaff, 1989). Empirical support for these programs is also increasing (Reynolds, 1981; Schleien & Ray, 1988). Increased appropriate social behavior, higher skill levels due to more appropriate models, greater acceptance from peers without handicaps, and greater enjoyment in integrated activities are some of the many benefits of these programs.

In the philosophy of normalization, persons with disabilities lead lives which are as culturally normative as possible. To do this, they must have opportunities and freedom to learn and enjoy recreational activities in normative and nonnormative programs. Similar to the experiences of persons without mental retardation, these recreational learning experiences should begin in childhood and the skills should be ones which can be used, to the greatest extent possible, in normal community recreational settings. For young adults who have not had the opportunity to learn these skills, the transition period can be a critical time to learn and obtain access these outlets. Family, friends, and professionals involved in recreation and leisure pursuits must work together to make such opportunities available and accessible.

## Economic Integration

Economic integration of young adults with mental retardation, as others entering adulthood, may be defined in terms of the process whereby they obtain and disburse income. The definition applies income from multiple sources including but not limited to employment, income maintenance, and other sources of payment (e.g., income from personal or family assets, insurance payments, court-ordered compensation). Employment may be further defined to include sheltered employment, group employment with support services, individual employment with support services, and competitive employment for at least minimum wage without support of a service provider (Lewis, Johnson, Bruininks, Kallson, & Guillery, 1991). Each type of employment may be part- or full-time.

Young adults with mental retardation may be eligible to receive income from federal Supplemental Security Income or Social Security Disability Insurance, often supplemented by state income support programs. The fact that these are individual entitlements paid directly to the person with disabilities or the person's representative payee offers opportunity for choices often not fully appreciated. In addition to direct cash benefits under these programs, young adults with disabilities may be eligible for Medicaid or Medicare benefits in addition to long-term care supports such as Medicaid Home and Community-based Services (Boggs, Haney-Maxwell, Lakin, & Bradley, 1988), and, soon, Community Support Living Arrangements. Personal income of young adults may also derive from sources other than paid employment or public funds. It is important to note that eligibility for public funds may be negatively affected by personal income and assets.

Not surprisingly, economic integration does not require paid employment. Unearned income, whether from public or private sources, can provide the basis for economic integration. While paid employment may meet the needs of some for personal income, feelings of achievement, sense of belonging and participation, and development of social relationships, others may choose to decline paid employment in favor of other activities, thus challenging those who advocate that all adults with disabilities should have both full employment and the right to make significant choices about their own lives. It is important to recognize that the right to choose, an essential component of normalization, is most respected in honoring choices with which one disagrees.

Paid employment with support services in an integrated workplace is seen as a desirable public policy goal (Dolan, 1989). Beyond the issue of the preferences of those who are to be provided such placements is the question of benefit and cost effectiveness. Job retention is clearly an unresolved problem for many young adults with mental retardation in supported employment as it is for many other low-skilled minimum wage employees (Schafer, Banks, & Kregel, 1991). Financial disincentives that may affect those employed are also a major concern (Schloss, Schloss, & Wolf, 1988).

Paid employment should be seen as a desirable, but not universal means to enhance community integration. Many Americans engage in no paid work but still enjoy acceptance within their

communities. The importance of unpaid volunteer work within our society is broadly recognized and offers diverse opportunities for meaningful and valued community participation. Society has a long way to go in recognizing and realizing the potential role of volunteerism by young adults with mental retardation in enhancing their own integration within the community.

Finally, economic integration of young adults with mental retardation requires that, to the greatest extent possible, their right to manage their own income is respected. Agreement with this principal is easily gained; more difficult is its acceptance in practice. Is the right to spend money foolishly included? May a young person with mental retardation demonstrate the same degree of disinterest in healthy diets as persons without mental retardation? Must young adults with mental retardation buy sensible clothing while all others seem to invest in disposable (and forgettable) fashions of the moment? Should the young adult with disabilities be allowed to choose a place of residence because of price alone, even when it is in a potentially unlivable neighborhood? These are many of the questions that must be resolved in the minds of service providers before expecting persons for whom they are responsible to do the same. While community integration of young adults with mental retardation is indeed facilitated by one's level of economic integration, traditional definitions of economic integration should be expanded to include options and sources of income other than simply paid employment.

## Support Services and Barriers to Community Integration

All young adults, including those with mental retardation, need a place to live, resources to meet their financial obligations and desires, supportive social networks, and opportunities to participate in meaningful activities. Developing the skills to independently select and participate in these activities is a major task of childhood and adolescence. During young adulthood, some skills continue to be developed, but the focus shifts to applying skills learned during childhood and adolescence to becoming as independent as possible.

Young adults with and without mental retardation vary in the degree to which they are able to independently take care of their own needs. For example, some young adults are able, at the age of

18 to find and maintain an apartment, and to live there without any assistance from family or friends. But everyone knows persons without mental retardation who require intermittent or ongoing support from family members for things such as obtaining a balanced meal, taking care of the laundry, or managing a household budget. Like young adults without mental retardation, there is great variation in the skills young adults with mental retardation bring to the task of independent living. Some, like those without mental retardation, are able to live with minimal support from family or friends. Others require assistance in many areas of home living possibly, including such basic needs as bathing and eating.

While individual support needs vary widely among persons with mental retardation, some studies have suggested common support needs. A 1990 national survey asked over 13,000 people with developmental disabilities and their family members what services and supports they needed to foster independence, integration, and productivity. The five most common support needs mentioned included: general medical services, dental services, transportation to work, school, or other daytime activities, case management (e.g., coordinating support services and resources), and income assistance (Temple University Developmental Disabilities Center, 1990). It is obvious from this list, that many of the support needs mentioned by persons with developmental disabilities are also needs for young adults in general. On the other hand, while not needed by the majority of persons surveyed, specialized services were needed by some respondents. Examples of supports needed by at least 25% of the sample included: homemaking assistance or training, community living assistance, employment services, vocational training services, communication and language services, and physical or occupational therapy. Behavior management assistance or training was needed by just under 25% of the respondents.

These examples of support needs are not exhaustive. A wide range of other supports may be needed by some young adults with mental retardation, yet, only some persons with mental retardation need any given one. An important point to remember is that each person with mental retardation is a unique individual with a unique combination of preferences, needs, and skills. By definition, young

adults with mental retardation have limitations in adaptive functioning which may lead to support needs, but individual assessments are required to identify the particular supports needed by each young adult.

While federal and state laws and precedential court cases have codified expectations that persons with mental retardation have opportunities to live, work, and otherwise participate in typical community settings, a number of barriers interfere with the provision of supports to facilitate such an outcome. Those barriers include limited resources (financial, transportation, medical, and other services), resistance from parents and community members, and client characteristics requiring skilled support. The remainder of this section includes a brief review of literature on these barriers.

*Lack of Resources*

Several hurdles related to a lack of available resources are evident as adolescents make the transition to adulthood. Three areas in which the hurdles are most evident are residential services, vocational services, and other support services.

*Residential Services.* For young adults with and without mental retardation, leaving public education is often accompanied by movement away from family homes into other living arrangements. For those without mental retardation, common non-family residential options include living alone or with friends in an apartment or home, living in military barracks, or living in housing associated with post-secondary education. While the majority (57%) of young adults without mental retardation move to independent living arrangements within a couple of years of high school graduation (Affleck, Edgar, Levine, & Kortering, 1990), outcomes for young adults with mental retardation are often quite different. For young adults with mild mental retardation, anywhere from 60 to 79 percent continue to live with parents after leaving school (Affleck *et al.*, 1990; Frank, Sitlington, Cooper, & Cool, 1990), while between 20 and 23 percent move to independent living arrangements. Among young adults with more severe mental retardation, between 36 and 60 percent move to community or institutional residential facilities, and almost all of the rest remain at home with family members (Affleck *et al.*, 1990; Bruininks, Lewis, & Thurlow, 1990). Of those who move out of home supported settings in recent

years, the greatest proportion moved to homes with 15 or fewer others who had mental retardation (Amado, Lakin, & Menke, 1990).

Some of the discrepancy between the residential choices made by young adults without mental retardation and those with mental retardation can be traced to specific resource barriers. One of those barriers is a continued reliance by funding agencies on institutions or large community facilities which provide a whole array of support services at a high cost whether a particular person needs each support service or not; rather than financing a specific set of supports needed for the person to live in a selected community residential setting. While the relatively new Home and Community Based Waiver program provides more funding flexibility than some traditional federal funding sources, the program is not available to all those who could benefit from it. The other major barrier facing young adults who want or need to leave home is a lack of a continuum of options. Several barriers were identified by 13,075 consumers with developmental disabilities in a recent national survey including: insufficient availability of community living alternatives, lack of affordable housing, lack of accessible housing, eligibility barriers, and funding barriers (National Consumer Survey; Jaskulski & Metzler, 1990). In summary, while the majority of young adults without mental retardation are able to find resources to move from parental homes within a year or two of leaving public school, a lack of resources prevents similar proportions of young adults with mental retardation from moving into independent or small supported community residential settings during the same time period.

*Vocational Services*. As in the residential area, there are major differences in work and day activities for young adults with mental retardation compared to those without mental retardation. Affleck, *et al.* (1990), for example, found that while nearly two thirds of young adults without mental retardation were competitively employed 30 months after high school graduation, only 47% of young adults with mild mental retardation were employed. Another study by Bruininks *et al.* (1990) found that for persons with moderate or severe mental retardation, the numbers employed competitively or in supported employment were only 29% and 6%, respectively. Clearly, young adults with mental retardation have experienced barriers to participation in typical employment settings. The 1990

National Consumer Survey identified a number of barriers to employment including: limited employment options, a lack of adequate non-work options (e.g., for those of retirement age), lack of support services to enhance productivity, low pay and lack of integrated opportunities for work, exclusion from vocational services due to eligibility requirements, lack of quality staff, and lack of resources for ongoing funding (Jaskulski & Metzler, 1990).

*Other Support Services.* Resource related barriers to social and leisure integration have been identified in several different reports (Temple University Developmental Disabilities Center, 1990; Thurlow, Bruininks, Wolman & Steffens, 1989; Thurlow, Bruininks, & Lange, 1989). Among the purposes of all of these studies was to identify barriers to participation in integrated community settings. The National Consumer Survey reported the proportion of people with developmental disabilities who needed but were not receiving specific types of services. In other surveys young adults with mental retardation were asked to identify reasons they could not participate in preferred community activities. The proportion of each sample which reported each of nine barriers have been summarized on Table 1. The lack of companion, friend or advocate services was the most common unmet need related to social and leisure participation reported by the individuals in the National Consumer Survey. All of the other studies identified this barrier as a lack of someone to accompany the person to desired activities. Between 21% and 57% of all persons surveyed identified the lack of a social companion as a barrier. Other common barriers were a lack of finances, and a lack of transportation for leisure activities. It is clear from these studies that more work is needed to facilitate the development of friendships to enable young adults with mental retardation to experience more integration in social activities and recreation.

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Insert Table 1 about here

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*Attitudinal Barriers*

Attitudinal barriers to integration have been identified among a number of different groups. For young adults who live in institutional settings, a major barrier to community living is resistance from their parents to deinstitutionalization. In a recent review of the literature, Larson and Lakin (1991) summarized evidence that an overwhelming proportion of parents whose sons or daughters live in institutions are satisfied with the institution (90%) and opposed to deinstitutionalization for their son or daughter (60+%). The reasons for their concerns range from fear that community settings are inappropriate for their sons or daughters to fears that deinstitutionalization would have a negative impact on the family. Interestingly, parents who were resurveyed after their sons or daughters moved to community settings were much more positive about deinstitutionalization, and were satisfied with community settings (80+%). Since most parents appeared to change their minds about the benefits of community living after deinstitutionalization, professionals, policy makers, and advocacy organizations interested in deinstitutionalization need to identify effective strategies to reduce the stress felt by parents prior to deinstitutionalization (Larson & Lakin, 1991).

Persons currently living in institutional or large community settings also face barriers due to opposition from community members. Some community members resist the development of homes for persons with mental retardation in their neighborhoods (Balukas & Baken, 1985; Gale, Ng, & Rosenblood, 1988; Lubin, Schwartz, Zigmond, & Janicki, 1982), an obvious effort to prevent young adults with mental retardation from entering the community. This barrier has been experienced during the deinstitutionalization movement and has been visible when, for example, communities used zoning laws and other practices to try to prevent group homes and other community living arrangements from being created in certain neighborhoods (Bates, 1986; Steinman, 1987). Lubin *et al.* (1982) reported that community members were concerned about negative impacts on property values, negative impacts on neighborhood character, and threats to neighborhood children. However, follow-up studies which examined these issues after community residences had been opened showed that neighbors reported generally indifferent or accepting attitudes after a home opened (Conroy &

Bradley, 1985; Gale, Ng, & Rosenblood, 1988; Lubin *et al.*, 1982), and the presence of persons with mental retardation in the neighborhood did not reduce property values (Developmental Disabilities Program, 1982; Ryan & Coyne, 1985; Weiner, Anderson, Nietupski, 1982). In another study, support for deinstitutionalization was six times more prevalent than for institutionalization among members of the general public (Wilmoth, Siver, & Severy, 1987).

A different sort of attitudinal barrier affects the transition of persons who reside with their parents during their young adult years. This barrier relates to the conflict between parent-advocacy and self-advocacy (Daniels, 1982). One important outcome for young adults with mental retardation, which was alluded to earlier in the social relationships section, is the transition from dependence in choice making to self-determination (Abery & Bruininks, 1990; Karan, Lambour, & Greenspan, 1990; Halloran & Henderson, 1990). Daniels (1982) suggested that conflict between what parents thought was best and what the young adult thought was best interfered with self-determination in four major areas: independence, peer group identification, sexuality, and goal setting for adult life. According to Daniels, barriers to independence in these areas are raised when parents ignore preparation for independent living, resist or prevent their young adult from participating normal developmental activities (e.g., spending the night at a friends, dinners out with friends, shopping), advocate for maintaining an asexual approach by withholding information, limit opportunities to develop relationships, and fail to advocate for needed vocational preparation. Daniels suggests that the conflict between parent advocacy and self-advocacy mirrors the developmental tasks of growing up, and that a transition to self-advocacy is necessary for the person with disabilities to become persons with their own voice. Ward (1988) identified not giving adolescents the right to fail and to learn from that failure as a major barrier to the development of self-determination. Mitchell (1988) suggested that overprotection, low expectations, and lack of stable support systems are major barriers to self-determination. These attitudes create barriers which may keep persons with mental retardation from developing self-determination during their young adult years.

*Personal Supports*

A final type of barrier limiting access to integrated community living for young adults with mental retardation is a lack of resources to support specific individual needs. This barrier is closely related to the lack of resources barrier but is a lack of resources to address specific needs such as challenging medical needs, challenging behavior, physical or sensory special needs, or extensive personal care needs in areas such as eating, dressing, or toileting. It is well-documented that persons with more severe mental retardation, more challenging medical needs, and/or more challenging behaviors are less likely to move from institutions to integrated community settings and thus more likely to be among those newly admitted to readmitted to institutions (Borthwick-Duffy, Eyman, & White, 1987; Vitello, Atthowe, & Cadwell, 1983; White, Lakin, Bruininks, & Li, 1991).

Support services available to people who exhibit behavior which is harmful to themselves, others, or objects are often insufficient to promote community integration. Challenging behaviors are more common among persons living in institutions than among persons living in integrated settings (Bruininks, Hill, & Morreau, 1988; Jacobson, 1982; Lakin, Hill, Chen, & Stephens, 1989; Scanlon, Arick, & Krug, 1982), and may be an important barrier to moving to smaller homes. However, challenging behaviors cause difficulty for persons living in small community homes as well (Jacobson & Schwartz, 1983). Persons with challenging behavior who live in small (1 to 6 person) homes have fewer opportunities for community integration than other similar individuals in the same type of settings (Larson, 1991). The barriers to integration from challenging behavior have been identified by researchers who found that 47% of people with mental retardation in community residences, and 53% of persons with mental retardation in institutional settings were limited in their community participation because of problem behaviors (Hill & Bruininks, 1984). Simply put, when adequate supports are not provided, persons with challenging behaviors face barriers to full integration, regardless of the setting in which they reside.

Like challenging behavior, the presence of more severe levels of mental retardation or the presence of more serious medical needs may also require increased support in order for integration to

be successful. Several studies and literature reviews have concluded that persons with more severe levels of mental retardation are less likely to participate in typical community activities no matter where they live (Bell, Schoenrock, & Bensberg, 1981; Dalgleish, 1983; Gollay, Freedman, Wyngaarden, & Kurtz, 1978; Hill, Rotegard, & Bruininks, 1983; and Lakin, Bruininks, & Larson, in press). Furthermore, persons with more severe mental retardation are more likely to live in institutions (Lakin *et al.*, 1988), and are much less likely to work in typical integrated settings (Wehman, 1991).

Despite these apparent barriers, however, people with challenging medical needs, challenging behaviors, or severe mental retardation can and do live successfully in community settings (Hayden & DePaepe, 1990; Larson & Lakin, 1989; Larson & Lakin, 1991; McDonald, 1985). These findings challenge the service delivery system to develop support strategies to provide all young adults with the opportunity to live, work, and play in integrated settings.

Beyond the need to address specific barriers which reduce access to or use of integrated residential, vocational, and recreational environments, is the need to ensure that the integrated services which are received enhance quality-of-life. Young adults, regardless of whether they have mental retardation or not, develop and strive to enhance their quality-of-life. It is becoming clear that physical presence in typical home, school, work, and leisure settings is necessary but not sufficient to enhance the quality-of-life for persons with disabilities. Knoll (1990) identified 11 characteristics of service environments which support quality-of-life: real choices in all aspects of daily life, instruction to develop functional skills, opportunities for interaction with a variety of people, use of "generic" services, access to community resources, age-appropriate settings and materials, access to a wide range of community environments, living in a typical neighborhood, meaningful daily activity, the use of non-aversive interventions, and opportunities to develop relationships with friends. Enhancing quality-of-life through removing barriers restricting access to integrated environments and through designing service systems which facilitate community adjustment is a major challenge for those who work with young adults with mental retardation.

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Table 1

*Barriers to social and recreation integration: Proportion of people with disabilities reporting each type of barrier*

| Type of Barrier | National Consumer Survey[a,e] | Foster/ Group Home Survey[b] | Post School Outcomes[c] | | Post School Outcomes[d] Cross-sectional Analysis | | |
|---|---|---|---|---|---|---|---|
| | | | Moderate | Severe | 7-10 yrs | 3-5 yrs | 1-2 yrs |
| No companion/friend/advocate services (no one to accompany the person) | **31%** | **21%** | **36%** | **33%** | **38%** | **44%** | **57%** |
| Lack of money | -- | **27%** | 18% | 10% | 14% | **25%** | **29%** |
| Lack of transportation - leisure, shopping, appointments | **23%** | 17% | **27%** | 3% | **25%** | 3% | 7% |
| Activity not available | -- | **25%** | 18% | **20%** | **24%** | 10% | 14% |
| Need Recreation/Leisure Services | **34%** | -- | -- | -- | -- | -- | -- |
| Lack of time | -- | **20%** | 15% | **30%** | 0% | 13% | 0% |
| Lack of skills to participate | -- | 15% | **21%** | 10% | 10% | 9% | 7% |
| Challenging behavior interferes | -- | 17% | 12% | 13% | 14% | 9% | **21%** |
| Need Self-help/Support group | **20%** | -- | -- | -- | -- | -- | -- |

*Note.* Percentages over 20 percent are printed in bold. [a] $N$ = 13,075; Temple University Developmental Disabilities Center, 1990; [b] $N$ = 336; Hill, Lakin, Bruininks, Amado, Anderson, & Copher, 1989; [c] $N_1$ = 33, $N_2$ = 30; Thurlow, Bruininks, Wolman, & Steffens, 1989; [d] $N_1$ = 21, $N_2$ = 32, $N_3$ = 14; Thurlow, Bruininks, & Lange, 1989; [e] This study reported the percent who need this type of service or support but do not currently receive it. All the other studies reported percentages who mentioned each barrier among those who experienced barriers to integrated activities.